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The Study of the Use of Advance Directives in Minnesota Nursing Homes as Perceived by Social Workers

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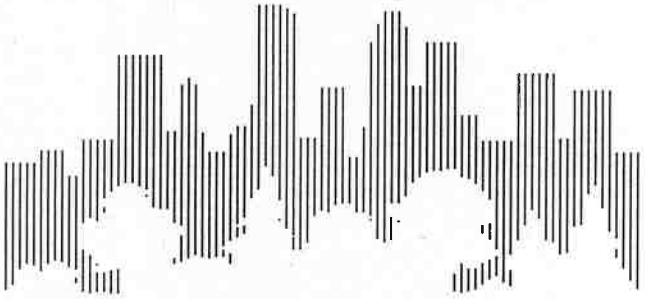

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MASTERS IN SOCIAL WORK THESIS

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THE STUDY OF THE USE OF ADVANCE DIRECTIVES IN MINNESOTA NURSING HOMES AS PERCEIVED BY SOCIAL WORKERS

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CERTIFICATE OF APPROVAL

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Abstract

The Study of the Use of Advance Directives
in Minnesota Nursing Homes as Perceived
by Social Workers

DENISE SIGSTAD

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This study sought to discover the use of advance directives as reported by nursing home social workers. The focus is on residents who are living in nursing homes and are sixty years old or older. One hundred social workers in Minnesota were randomly surveyed on the current rate of advance directive use, barriers to completing the forms, and perceptions from social workers about whether they have or not have adequate knowledge and education to teach about advance directives. A review of the literature on advance directives shows the average use is only 5-18% for the elderly population.

Survey findings confirm that the average use of advance directives is similar to the general average for the elderly population. Common barriers include procrastination, fear of death and dying, dependence on family members to make decisions, and lack of knowledge of advanced directives. Many social workers perceive they have adequate training and education on advance directives, but are open to further information on state laws and medical terminology. Further implications for social work practice include continued research on advance directives. The research shows that even with new forms combining living will and health care power of attorney forms, there is a lack of understanding by the elderly population.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1

INTRODUCTION

Background of the Problem

Nearly 90% of all Americans will have some form of a managed death that takes place in a nursing home, hospital, or other health care setting. Out of this 90%, only about 10-15% of people have any written document stating their wishes at the end-of-life. People over the age of sixty-five account for 73% of the deaths in the United States and 30% of this 73% do not have a spouse, friend, or family member who is able or willing to speak for them and their end-of-life care needs (Haynor, 1998). It is estimated that by the next century about 20-25% of the population will be over the age of sixty-five and there will likely be increased demand for home health care services, hospice, and family respite care (Germain, 1983).

The Federal Patient Self-Determination Act (PSDA) came into effect December 1991 to give guidelines to health care facilities regarding the use of advance directives (LaPuma, 1991). This Act does not require patients to have advanced directives, but it does state that patients have the right to make informed decisions on their own health care needs (Pellegrino, 1992). For health care facilities to be in compliance with the Act, they must provide three items for Medicare and Medicaid reimbursement contracts. The organizations need to: document if a person has an advance directive, implement policies in facilities for advance directives while

not discriminating against people who have or do not have advance directives, and educate staff and community members about advance directives yearly. Even with the Patient Self-Determination Act in place only 5-17.5% of adults have completed an advance directive (Sansone, 1995).

One important factor about advance directives is that it states a person's right to accept or refuse certain treatments and medical care (Robertson, 1991). Many literature reviews on advance directives have shown that even with the Patient Self-Determination Act in place that there has not been a drastic change with the elderly population completing advance directives forms.

In many past studies there appear to be more barriers than benefits to using advance directives. This research looked at some common barriers and the use of advance directives in nursing homes. The application of this research could give direction for future use of advance directives in nursing homes throughout Minnesota and possibly in other states.

Statement of the Problem

The purpose of the research study was to explore the current use of advance directives in nursing home settings throughout Minnesota. The study provided some information about potential barriers of the use of advance directives from the perspective of the nursing home social workers. The study focused on a random sample of nursing home social workers in Minnesota who are mandated by the Patient Self-Determination Act of 1991 to inform clients of their right to use of advance

directives (Pellegrino, 1992).

Purpose and Significance of Research Study

The purpose and significance of this study was to increase the knowledge of why people in the nursing home population do or do not use advance directives. This study is significant because future research and social workers may look at this study for ways to increase discussion and know barriers of elderly population in nursing homes when completing advance directives.

An elderly person's chances of recovering from medical problems that would have been fatal in the 1970's has increased due to advances in medical technology which increased the life expectancy of people. As advances continue elderly people are faced with decisions that will affect their quality of life (Galambos, 1989).

Research Questions

The following are the three questions that were answered in the research study:

1. What is the current rate of advance directives used in Minnesota nursing homes by the population age 60 or over?
2. What are some of the barriers to the use of advance directives in nursing homes?
3. Do nursing home social workers in Minnesota perceive they have adequate information and training to educate the elderly population about advance directives?

Summary

This chapter has introduced some issues of advance directives that are faced by the older adult population. The following chapters include literature review, theoretical framework, and the research results related to use of advance directives. "There is increasing issues that are coming to terms with end-of-life issues, making informed decisions, and ensuring that loved ones are untroubled by these decisions and that society honors them are vital life tasks for everyone" (Kaplan, 1995, p. 866). The more aware a person is of his/her own values and preferences regarding life and death health care, the easier it will be to make better decisions about advance directives (Stum, 1996).

CHAPTER 2

LITERATURE REVIEW

Definition of Advance Directives

To clarify important terms of advance directives the following section defines terms, decision-making guides, and examples and situations when a living will or health care power of attorney form can be used.

Advance directives: A way for an individual to express his/her beliefs and values in a written form that is used as a guide in the event of incapacity. The two common forms are living will and health care power of attorney.

Durable power of attorney: "A legal document in which an individual (the principal) appoints an agent (designated decision maker) to make health care decisions if the principal is unable to make or communicate his or her own decisions. Health care decisions are broadly defined and can include any care, treatment, service, or procedure to maintain, diagnose, or treat a person's physical or mental condition" (Stum, 1996, p. 12). See Appendix B.

Living will: " A legal document in which an individual can specify the types and extent of health care treatment he or she may prefer when terminally ill and can authorize a proxy (designated decision maker) to make health care decisions for him or her. A living will only goes into effect when the individual is unable to make or communicate health care decisions (incapacity) and when a terminal condition exists" (Stum, 1996, p.12). See Appendix A

Health care agent: A person who is legally authorized to make health care decisions on behalf of another person who is incapable of decision making. The agent is designated by the principal who is the individual creating the health care form (Stum, 1996).

Health care proxy: The proxy is the term used on the living will form to legally name a person to make decisions for the individual when the person is terminally ill or incapacitated (Stum, 1996).

Additional terms that are used in the living will form include ventilator/respirator, nutritional support and hydration, dialysis, cardiopulmonary resuscitation (CPR), and use of antibiotics.

Ventilator/respirator: "A breathing machine for a person unable to breathe on his or her own. It is not possible to talk or eat while on a respirator, so artificial feeding may be needed" (Stum, 1996, p.6).

Nutritional support and hydration: If a person cannot take food or fluids be mouth, nutrition can be given through tubes that are placed in the nose, stomach, or small intestine. Tubes placed in the stomach or small intestine require surgery for placement of the tube. Without this feeding death will come more quickly, but a person can remain very comfortable and pain-free without a tube feeding (Stum, 1996).

Dialysis: "A mechanical means of cleansing the blood when the kidneys are not working" (Stum, 1996, p.6).

Cardiopulmonary resuscitation: A procedure that is used to

restore a person's heartbeat and breathing (Stum, 1996).

Antibiotics: Used to treat an infection and may prevent the person from a serious infection, but does not affect other health problems. Antibiotics only stop the infection and does not cure the person or have any long-term effects for end-of-life care (Stum, 1996).

In the literature review there are not specific examples of people regarding advance directives, but a person can think about the quality of life he/she wants by using the following situations for health care decisions. A person must consider if he/she has a terminal disease or condition, which means a person has an incurable or irreversible condition for which medical treatment will only prolong the dying process and the moment of death. If a person has severe and permanent brain damage or injury with little chances of regaining any consciousness, (called persistent vegetative state), medical treatment can be used to sustain a person's heartbeat and vital organs for an indefinite time to keep a person alive (Stum, 1996). All of these situations can be considered when talking about end-of-life care and should also be discussed with family members.

When completing advance directives it is important to have in writing wishes for end-of-life care and to consider what are important choices for each individual. Everyone is entitled to "reasonable medical practice" which includes maintaining a person's comfort, hygiene, and human dignity no matter if an advance directive is available or not (Stum, 1996, p.5). Some guides that an individual can think about before writing an

advance directive are what are the most important things they want for end-of-life care. For example it is important for some people to be as pain-free as possible and to maintain the highest possible physical and mental functioning possible. Others may look at the ability for them to refuse or withdraw treatment when the chance of a cure or meaningful recovery is only prolonged. There are many issues that a person needs to consider when completing an advance directive (Stum, 1996).

History of Advance Directives

In the 1960s and 1970s health rights advocates promoted the issues of access, equality, and utilization at the individual patient level. Advocates for stronger patients' rights in the legal and professional arenas were among the most successful strategies used during this time. "With the passage of Medicare and Medicaid in 1965 and the myriad of other federal health legislation, federal involvement in funding and monitoring of health care system was legitimized" (Mizrahi, 1992, p.247). With these new statutes and regulations at the state and federal level this increased the respect of patient rights to make end-of-life decisions. By the late 1970s the attention of policymakers turned to controlling costs and access rather than expanding the number of health services (Mizrahi, 1992).

National efforts to promote advance directives occurred in the 1970s and 1980s after the two famous cases Karen Quinlan and Nancy Cruzan who were kept alive for years in vegetative states against the wishes of their families (Rosen, 1998). These two landmark cases forced the U.S. Supreme Court to deliberate over

states' rights to refuse life-sustaining treatment for a terminally ill patient (Galambos, 1989).

In 1983 following a severe car accident physicians diagnosed Nancy Cruzan, aged 24, as being in a permanent and irreversible vegetative state. Over the seven years that Nancy was on life-support her condition continued to deteriorate and her parents believed Nancy would not want to continue to live by machines. As a result of her condition her family fought in court to remove her from life support in the state of Missouri and when they were not granted permission to remove the life-support machine Nancy's parent took the fight to the U.S. Supreme Court. The Supreme Court supported the issues of advanced directives and Nancy was finally able to die peacefully after years on life-support when she was removed from life-support and artificial nutrition and hydration (Kaplan, 1995).

In 1976 Karen Quinlin, aged 27, was in a New Jersey hospital and deemed to be in an irreversible coma and she became dependent on mechanical respiration and artificial nutrition and hydration. The Quinlin case was the first public debated case when it was brought to the New Jersey Supreme Court by her parents in May 1976. The court again favored patient rights and overturned physician decisions and her parents were granted the permission to remove the respirator. This decision was the first state supreme court decision and was critical for patient's rights for two reasons. The first reason is that the judicial system recognized the Constitutional right to refuse treatment and that individuals have the right to make decisions even if

the refusal to treatment might end their lives. The second reason is that in the absence of a formal advance directive a patient's family could provide effective substituted judgment and, in consultation with a physician, make end-of-life decisions without resorting to the courts (Kaplan, 1995).

Because of these cases and many other similar cases regarding life-sustaining treatments by 1992 all fifty states and the District of Columbia passed legislation recognizing some forms of advanced directives (Kaplan, 1995).

Studies have shown large numbers of elderly people have a willingness to address future medical decision making after being educated on their options and choices (Bailly, 1995). Even though the Patient Self-Determination Act (PSDA) is a federal act, there are many differences across the United States with the living will and health care power of attorney forms. High (1993) speculates that the low national rate of advance directive use is due to lack of information and lack of encouragement from health care professionals and family members. A survey conducted in 1993 by the Joint Commission on Accreditation of Health Care facilities said implementation of the PSDA has been flawed. The survey showed many health care facilities either do not have a policy or have a minimal existing policy on advance directives (Kaplan, 1995).

Living Will and Health Care Power of Attorney

The two forms of advance directives are the living will and health care power of attorney. Many research studies look at living will and health care power of attorney separately and

studies include comparing the two forms or small studies on one or the other of the forms. A living will has been described as being most appropriate for people who do not have someone they can trust with decision-making power (Pellegrino, 1992). See Appendix A. People can specifically dictate the kinds of end-of-life support they desire and the conditions under which these treatments are to be used. Having a living will empowers people by giving them a sense of control over their future health care decisions. The living will can also provide a workable rule of non-treatment decisions that respect the person's autonomy without compromising respect for incompetent patients (Robertson, 1991). In Appendix A the example of a living will form is three pages in length and states that it is a legal document that is to be used to help family, doctors, and any other person concerned with end-of-life care. The document describes that the living will is in effect unless the principal (the individual executing the document) amends the form or revokes it. It encourages the individual to review the document often to make sure it continues to express health care wishes. The living will form has seven statements that the person is to respond to that include wishes of what treatment is wanted and not wanted such as ventilator, CPR, tube feeding that gives the individual the chance to write health care needs. There is also a section that the individual can designate a proxy that is someone to help carry out his/her wishes and if the person becomes unable to communicate the proxy can become the guardian or conservator for the person. Some people like the living will

form because he/she can state certain preferences and specific treatments that are requested. The living will needs to be witnessed by two people over the age of 18 and not by the person designated as the agent, or witnessed by a notary public to be legal.

One drawback of the living will is that many older adults fear having to talk about death and dying issues with family members as death is often a taboo subject (Galambos, 1989). Another drawback is that a living will specifies treatment needs in terminal illness and is not effective when a person can voice his/her own needs. For this reason it can be seen as limiting the usefulness of the form (Emanuel, 1993). There also is the possibility that a patient may change his/her decision or there are changes and conditions that are different from what the patient anticipated and there are not specific instructions written in the living will to care for the person. It is also possible that the directive may not be available when needed, or not honored by family members or medical professionals (Emanuel, 1993). The living will also overlooks the fact that at different stages and times of life we have different interests and thoughts (Robertson, 1991).

The second type of advance directive is the health care power of attorney. See Appendix B. The health care power of attorney has greater flexibility of use and is perceived as more relevant to the patient's actual condition. This directive also provides for greater involvement of another person to help the patient make decisions (Pellegrino, 1992). While living wills

often limit treatment to terminal illness, a health care power of attorney can be a delegated authority when a patient is unable to voice his or her needs, or is incompetent prior to terminal illnesses (Orentlicher, 1990). The health care power of attorney form found in Appendix B is the written document that gives the individual (principal) the chance to state who he/she wants to help make health care decisions that include consenting or withdrawing care, treatment, and to treat physical or mental conditions. This form is specifically for Minnesota residents and the agent needs to be in compliance with Minnesota state laws for following health care decisions. The document gives the principal the opportunity to designate an agent and also an alternative agent, but does not allow in writing any further health care wishes which differ from the living will. This form needs to be witnessed by two people over the age of 18 years old and not people who are designated as the agents, or signed by a notary public to be legal.

One common drawback with this directive is that the designated person may not make the same choices the patient would make, especially if it would involve withdrawing or terminating life-sustaining treatments. The important thing is that the proxy and patient discuss ahead of time the wishes and needs of the patient. One study did note that only 16%-55% of patients with proxies have discussed preferences of life-sustaining treatment wishes (Emanuel, 1993). A family member is designated in about 80% of all cases, but often a proxy may not exactly follow a patient's preference and wishes. A proxy may be

more hesitant to withdraw or terminate life-sustaining treatment than the patient is. The burden of decision-making can be heavy on the proxy (Emanuel, 1993).

No matter if a person is using a living will or health care power of attorney, it is important that his or her doctor, friends, and family have a copy of the directive so they are aware of health care decisions (Richmond, 1990). People are able to have both a living will and health care power of attorney, but it is not necessary to have both and it is important that the two forms do not contradict each other on any issues of health care. If someone has both forms and there is a contraction it is possible neither forms would be honored or some states look at the form that was most recently prepared to take precedence (Stum, 1996).

Barriers and Benefits

Some elderly people even when educated about options may choose not to write down wishes. Some people prefer and expect that elderly people will involve family members in health care decision-making (Bailly, 1995). Advance directives can be too vague and must be interpreted by surrogates at some later time (Danis, 1994). Emanuel (1993) found evidence that indicates that of all advance directives that were completed, only 31% were available when life-sustaining treatment decisions were being made, and 28% were ignored or overridden even when available. Emanuel (1991) listed lack of physician initiative as the major barrier to people completing advance directives.

Additional barriers include family, physician, and health

care facility objections to the use of advance directives. Family members often think they know the patient's real wishes even if end-of-life care was never discussed. When some family members are faced with making life and death decisions it is an emotional time and many are unable to cope with the potential death of the loved one and may seek to prevent the death by not following the advance directive. It is also possible that family members differ in their own preferences of care and not the patient's especially if it involves withdrawing life support or other end-of-life treatments (Emanuel, 1991).

Physician opposition can occur if an advance directive calls for cessation of life-support at a premature stage according to good medicine and care. Another reason that physicians override a directive is because the family objects and the family represents a potentially vocal and disruptive element to the doctor and pose a threat of legal recourse if a physician terminates life-support contrary to the family's wishes. This is also a difficult situation because the family may request medical care that would be more harmful to the patient or unrealistic to the patient's health condition (Emanuel, 1991).

The third area is opposition from health care facilities that provide end-of-life care. Many hospitals and other health care facilities have ethic committees to discuss difficult cases involving patients on life support and to make sure that the institution is following policies and seeking the highest moral ground and following the patient's wishes. If an

institution is unable to follow a patient's advance directive a patient can be transferred to an institution that will be able to better follow the directive (Emanuel, 1991).

A benefit to completing an advance directive is that there is a written document stating health care wishes. Stum (1996) gives five ways to avoid common mistakes when completing an advanced directive. It is important that the individual: shares what he/she wants and does not want for treatment, he/she leaves instructions that are not too specific or vague that they are of no help to the agent or proxy, avoid terms with no standard meaning (e.g. like a vegetable, nothing heroic). Also include guidelines or goals that can help others judge the benefits and burdens of health care procedures in varying situations (e.g. goal is to be as pain-free as possible and comfortable). Last is to avoid trying to predict all types of health care situations that might occur. This can be overwhelming and impossible and the agent should understand the overall concerns and goals of health care needs.

Legal Responsibilities and Rights of Agent

In the discussion about the health care power of attorney form the agent is in charge of making health care decisions on the principal's behalf and becomes the voice of the person. The three criteria listed by the Patient Self-Determination Act is that a person must meet to be an agent in any state are: over 18 years old, designated by the principal to make health care decisions, and he/she must consent to act as an agent (Dixon, 1993). A health care agent's responsibilities do not legally or

ethically begin until an attending physician determines the principal (patient) does not possess the capacity to make decisions. "A health care agent has no legal duty to act. If a person agrees to be an agent and then for any reason is unable, unavailable, or unwilling to act, that person may freely choose not to act without fearing any legal action. Principals are encouraged to name alternate agents in the event such situations occur. It is a gross misdemeanor offense to willfully conceal, cancel, or deface a living will or health care power of attorney without the principal's consent. Legal penalties can apply if there is an attempt to falsify or forge a living will or health care power of attorney" (Stum, 1996, p. 28). An agent is not subject to criminal prosecution or civil liability for any health care decision that he/she made in good faith (Stum, 1996).

The health care provider must take all reasonable steps to comply with the request of the patient or must transfer the patient to another facility that can comply with the patient's wishes. The health care provider must believe that decisions being made for the patient are consistent with the advance directive and if the provider administers treatment necessary to keep the patient alive, there are not legal repercussions. Even despite the agent's decision to withhold or withdraw health care the provider is not subject to criminal prosecution, civil liability, or professional disciplinary action as long as the provider gives the opportunity to transfer the patient to a facility that will comply with the directive (Dixon, 1993).

Research Findings

The Patient Self-Determination Act (PSDA) of 1991 assumes that the receipt of written information will encourage patients to complete advance directives. Some studies have shown this is not accurate, as advance directives are still not widely completed in the United States. The Act requires that patients be informed of their rights in the state they live in as directives vary from state to state (LaPuma, 1991). Kirmse (1998) completed a study and found ten common barriers that keep people from signing advance directives. The barriers include: (1) procrastination, (2) dependence on family member for decision making, (3) lack of knowledge about advance directives, (4) difficulty with discussing the topic, (5) waiting for the physician to initiate the discussion, (6) the physician waiting for the patient to initiate the discussion, (7) patients believe they need a lawyer to fill out the forms, (8) fatalism, or acceptance of the will of God or higher power, (9) fear that it means signing his or her life away, and (10) fear of not being treated for any medical needs if an advance directive is in place.

A study by Gamble (1991) involved seventy-five ambulatory people between the ages of 60-80 who attended a community dining site run by the Council on Aging. They completed a questionnaire about living wills and 52% of them said they were familiar with the state legislation on living wills, but they were confused with terms of terminal and extraordinary means. 24% said their

doctors know their wishes, 7% said the doctor did not know their wishes, and 69% were unsure if their doctor knew their wishes regarding end-of-life care. 81% said they wanted the opportunity to discuss their preferences regarding life-sustaining treatment with their doctors. The survey results show that many people are reluctant to sign a living will due to the lack of knowledge about the form and lack of communication from physicians regarding living wills (Gamble, 1991).

It appears that patients and doctors are waiting for the other person to ask questions about advance directives, and neither of them are initiating the conversation (LaPuma, 1991).

Very little research has been completed on the impact of advance directives upon decisions at the time when life-threatening events occur. For nursing home residents some of the directives were left at the nursing home and did not get sent to the hospital, some treatment choices were not applicable in all circumstances, and the directives are not always followed. Care is most likely to be consistent with previously expressed wishes if the patient remains competent (Danis, 1994). Some reports confirm that the existence of advance directives may not lead to care consistent with a patient's wishes unless a surrogate vigorously asserts the validity of the directive. Physicians can be more involved by personally discussing patient wishes when health conditions change (Danis, 1994).

Davidson (1986) suggests that the family physician should assume the major share of responsibility for helping patients' sort out treatment decisions and state those decisions in the

form of advance directives. Physicians should be aware of their attitudes and tone of voice when discussing advance directives, as it is a delicate topic. A barrier noted by physicians was that if they inform seriously ill patients about their condition it could prove harmful to the patient. Also many physicians are uncomfortable discussing death and dying issues with patients (Davidson, 1986).

Stum (1996) discusses how family members can be more effective in following a patient's advance directive and to know the loved one's wishes. As with most individuals they like to keep health care decisions in the family because he/she trusts the decisions of family and feel that the family knows the individual on a personal level. Family members can be effective support systems and proxy's (agents) for the individual by: listening to the individual and his/her health wishes, willing to be the proxy and taking the role seriously, by knowing the individual's beliefs and values about death and dying, and able to advocate for the individual's decisions about end-of-life care (Stum, 1996).

Cultural and Race Issues with Advance Directives

In the literature there was indications noted that when discussing advance directives health care providers need to be sensitive to cultural issues and to approach individuals with different cultures and religions carefully. "Those who have experienced discrimination throughout their lives may distrust the intent of health care providers with respect to advance directives" (Mezey, 1996, p. 207). There are many nonwhite

communities that may discourage or prohibit discussions of death and dying. When discussing advance directives the discussion should be translated into the patient's preferred language to ensure that the information shared is accurate and understood. For reasons not discussed in the article by Mezey (1996), is that people of other demographic groups are less likely to be approached to discuss advance directives even when the health care providers are to discuss the topic with every patient. One reason that African Americans and Hispanics are less likely to complete advance directives is from lack of information and knowledge (Mezey, 1996).

Another article by Haynor (1998) discussed a study of 1,193 elderly people who were asked about life-support preferences, CPR (cardiopulmonary resuscitation), or no CPR, and if they had living wills or health care powers of attorney forms. The subjects included 385 Caucasians, 364 African Americans, 288 Asians, and 156 Hispanics. "Though the study was limited the results suggested that significant differences exist between these groups" (Haynor, 1998, p. 31). African American respondents were significantly more likely to select CPR and less likely than Caucasians and Hispanic respondents to have documented end-of-life health care wishes. Caucasian respondents were more likely than any other group to have written advance directives and not want CPR. Asian respondents were most likely to select no CPR, but less likely to have written directives. Hispanics were more often likely to choose CPR and less likely to have written advance directives than any other group (Haynor;

1998). The study suggests that cultural attitudes must be considered when approaching people and families about end-of-life decisions. "There is not a one-size fits all ethic that fits all cultures" (Haynor, 1998, p.31). The study stated that "cultural attributes offered to explain these differences include the importance of religion and close family ties in African American and Hispanic communities and the belief among many Asian cultures that talking about death can bring about bad luck" (Haynor, 1998, p. 31).

Research on Nursing Home Patients

Advance directives open a window to dying with dignity and the avoidance of expensive, invasive procedures. The nursing home setting is an opportune locale to inform people of advance directives because many nursing home patients are likely to confront terminal illness in the perceivable future. The study shows that nursing home patients are willing and eager to express advance directive preferences (Diamond, 1989).

One misconception residents of nursing homes have is that someone else will enact the advance directive before the appropriate time and withhold other necessary treatments. It is noted that healthcare workers who guess at what a patient's resuscitation wishes and other health care preferences are only guessing and not effective in most cases (Dunlap, 1997).

Role of Social Workers in Nursing Homes

The roles of social workers should be educator, counselor, and advocator for using advance directives. Social workers should be able to educate residents about advance directives and

the legal options that are available. As a counselor the social worker will need to recognize the psychosocial factors involved in client's decision and support his/her choices in end-of-life care. Social workers should also advocate for residents by seeking other legal assistance or pastoral care and by being aware of changes in advance directives in relation to resident autonomy. Social workers have an ethical responsibility to promote choices for clients in the use of life-supporting systems (Galambos, 1989). They also need to be sensitive when discussing advance directives and choose appropriate times to discuss them. Needs assessment research can be valuable for social workers to determine whether, when, and how to engage elderly populations in discussion about future health care (Bailly, 1995).

Because the mission of the medical profession is to save lives and physicians receive limited skills training for counseling in medical school, many physicians experience discomfort introducing advance directives to their patients and often do not bring up the topic, waiting for the patient to discuss it first (Bailly, 1995). Rosen (1998) states that social workers should become central to the process of promoting advanced directives as they have had training in directives and medical terminology. In 1998, the National Association of Social Workers (NASW) formed a partnership with Care Source, a health communications firm, to provide materials to social workers to help discuss advance directives with clients (Caresource, 1997).

Literature Gaps

Advance directives, including living wills and health care power of attorney, are designed for directing health care decisions. A gap in the literature shows that there has not been a research study available that has looked at social workers in health care settings to see what barriers and benefits would be most helpful for them to know in order to teach advance directives to residents. Many studies in the literature review focus on the barriers of advance directives, and not much on ways to improve advanced directives or changes needed to increase the use of advance directives.

In the literature review there was limited discussion on advanced directives related to cultural and race issues. When articles such as Haynor (1998) and Mezey (1996) did discuss these issues it was brief and did not describe the initial research. Additional research and studies would be important to learn more about advance directives with different cultural groups.

One recent change is in the State on Minnesota of the Law 1998; Chapter 399 entitled Health Care Directive that took effect on August 1, 1998. See Appendix E. This new law was written by Senator Junge and combined the living will and health care power of attorney into one form. The new form was designed to make it easier to read, understand, and combine the two forms together (Junge, 1998). The goal is to provide more flexibility in the use of health care directives. In this new form there are more simple questions and the form adds a funeral directive that

a person can state wishes for burial or cremation and more about the individuals beliefs and values. This new law does not mean that the old living will and health care power of attorney forms are no longer in effect as long the forms continue to meet the following criteria. The directive must be completed by the person who the directive involves, give the date the form was completed, contain a health direction, witnessed by two people or notarized to be legitimate in the State of Minnesota (Junge, 1998).

It is important for a person to know that if he/she travels or lives in two different states that advance directives should be completed in both states. Many states have different requirements on advance directives and some states require that the directives be reviewed every two years. Overall, 47 states and the District of Columbia have living will directive statutes and 30 states have health care power of attorney statutes (Richmond, 1990).

CHAPTER 3

THEORETICAL FRAMEWORK

There are several theories related to advance directives including the *narrative theory of personhood, ecological theory, and the ego theory of psychology.*

Narrative Theory of Personhood

The *narrative theory* relates the attempt to project the autonomy of the individual into the future by writing down health care needs and decisions when still capable of making decisions which is the goal of an advance directive. The theory states that our decisions now should be binding even when we enter a state in which our values and interests have changed (Tonelli, 1996).

Factors that can change values include severe illness or loss of cognitive functioning. The narrative theory demands that previous wishes based on past interests should bind the person in the future despite any current changes in values and interests. Use of an advance directive would increase the likelihood that autonomy would be clear to others even in the process of changes including the loss of cognitive functioning. The attempt to validate the advance directive requires seeking information about a person's past preference and interests, and weighing them to the current physical and mental state the person is in (Tonelli, 1996).

According to the philosopher Derek Parfit, the personal

identity of a person depends at least in part on psychological continuity. Derek Parfit feels that, "when the strength of connectedness falls below a certain threshold there are philosophical grounds to claim we are, in fact, dealing with a different person" (Tonelli, 1996, p.817). For example a person makes out an advanced directive and then becomes cognitively impaired with dementia and unable to make decisions related to past interests and values. Family members and others could philosophically claim that this is a different person so the advance directive does not apply. To honor the advance directive may require actions that counter the current interests of the person as cognitive impairment is now present and the person has seemingly become a different person. Narrative theory suggests this person remains an individual and the prior choices expressed should be valued as related to past interests and values and not any current changes (Tonelli, 1996).

Ecological Theory

Ecological theory hold the view that human needs and problems are generated by transactions between people and their environment (Germain, 1980). Ecology relates to the understanding of relationships between a person and how the person maintains himself or herself by using the environment and shapes it to meet his or her needs without destroying the environment. Within the ecological theory is the life model which states that people are constantly adapting in an interchange with many different aspects of the environment. "Human beings change their physical and social environments and

are changed by them through the process of continuous adaptation" (Germain, 1980, p.5). When reciprocal adaptation is successfully achieved it supports the growth and development of people within their own environment. The life model of ecological theory notes that people must maintain a good fit with the environment and receive information by inputs and outputs in order to have a healthy life and continue to develop (Germain, 1980).

In the life model a family is viewed as a system of interacting parts that are contained within a set of boundaries that define the family and the environment. The family system has a set status and role so that the system can fulfill its function within the environment. Some transitions that can alter or place stress on the balance in the system include illness or cognitive changes in a person. The family must then deal with the changes and learn how to adapt in the environment to maintain a balance. The goals of the life model are to strengthen the adaptive capacities of people and to influence their environment so that transactions and changes become more adaptive and less stressful on the person (Germain, 1980).

Related to the use of advance directives, the directive can be used to assist in decreasing the stresses in the person and family by already having some set guidelines prior to changes in health needs. It is suggested that an advance directive be reviewed and updated every two years to be consistent with the person's current needs. A pitfall of an advance directive is that it can be changed only when a person is mentally competent

and able to make rational decisions.

Ego Theory of Psychology

The third theory relates to *ego psychology* and the concepts of defenses and denials. The theory's focus is on human behavior as it relates to origins, development, structure, and functioning of the ego, and its relationship to other aspects of the personality and the external environment (Turner, 1986). This theory also emphasizes the importance of an individual's adaptive capacity and its link to the social environment. Its view is that people are born with an innate capacity to function adaptively as they engage in lifelong development processes that shape the external environment. The ego is the part of the personality that contains the basic functions essential to individual successful adaptation to the environment throughout life (Turner, 1986). The ego mediates conflicts between the individual and the environment and also the internal conflict among the different aspects of personality.

Defense and denial both relate to the use of advance directives. Defense is used to protect the individual from anxiety by keeping intolerable or unacceptable impulses or threats from conscious awareness. Such defenses enable a person to function optimally to be effective under acute stress, or illness. A second type of defense is denial which involves a negation or nonacceptance of important aspects of reality or of one's own experience that may be perceived (Turner, 1986). The application of ego psychology to advance directives can help explain some of the barriers or responses of people who may

complete the advance directive. Some people may feel defensive or deny not feeling well; thus they put off completing an advanced directive to avoid the fact of dealing with changing health conditions.

Galambos (1989) views hope as a critical element in maintaining a positive psychological balance and which may enhance the ability to cope with chronic illness. Denying that life eventually will end, and denial of one's own mortality are coping mechanisms that allow elderly people to deal with aging and to distance themselves emotionally from reality. Individuals who use denial to cope would not be able to prepare for a terminal condition because he/she has not allowed himself/herself to think in these terms (Galambos, 1989).

Chapter 4

Methodology

Restatement of Research Questions

This research explored the following questions related to advance directives:

1. What is the current rate of advance directive use in Minnesota nursing homes by the population age 60 or over?
2. What are some barriers to the use of advance directives in nursing homes?
3. Do nursing home social workers in Minnesota perceive they have adequate information and training to educate the elderly population about advance directives?

Research Design

This study completed in the Spring of 1999 was an exploratory research design that uses common themes from the responses of social workers. The twelve questions of the survey were designed to answer the three research questions and to report the data as information about advance directives. There were no interviews or other direct contact with the participants. Data was analyzed for common areas that need strengthening in the use of advance directives. For example, if many of the social workers think they are not adequately trained to educate people on using advance directives, this information could be shared with nursing home organizations to see if some services could be added in this area.

Key Concepts and Terms

Some important concepts related to the research study need to be defined to understand the purpose of the study.

Advance directives: An advance directive is a legal written document that states how health care decisions should be made if the individual's ability to make decisions is lost (Caresource, 1997). Any person who has the ability to understand his or her own choices can complete an advance directive. The two types of advance directives are living wills and health care power of attorney.

Patient Self-Determination Act (PSDA): An act that Congress enacted in 1990 to encourage patients to complete advance directives. "Compliance with the act is a condition for Medicare and Medicaid reimbursement and is tied to institutional Medicare contracts" (LaPuma, 1991, p.402).

Self-determination: is the freedom of a person to determine one's own fate or course of action.

Living will: A written form that documents a person's wishes when terminally ill, including wishes regarding such medical life-support systems as tube feeding, cardiopulmonary resuscitation, and breathing machines (CareSource, 1997).

Health care power of attorney (Durable power of attorney): A legal instrument authorizing a designated person to act on behalf of a person who is incapable of making one's own decisions (CareSource, 1997).

Cardiopulmonary Resuscitation (CPR): An emergency step to restart a person's heart and breathing after they have stopped (CareSource, 1997).

Do not resuscitate (DNR) order: A physician's order to not start cardiopulmonary resuscitation (CareSource, 1997).

Nursing Home Social Worker: A social worker working in a nursing home who is required to inform patients upon admission about their rights regarding advanced directives.

Barrier: A boundary or limit that acts to hinder the effective use of an advanced directive.

The unit of analysis is each individual social worker in a nursing home setting who is required to inform clients of their right to use advance directives. The social workers surveyed were currently employed in Minnesota nursing homes and the questionnaires were mailed to them and required that they do not identify themselves in order to remain anonymous.

To effectively measure the knowledge of the terms and concepts required the above definitions. The terms measured by the questions describe the use of advance directives and how they relate to the elderly population in the nursing home. The questions asked the social workers how familiar they were with the terms living will and health care power of attorney. The purpose of many of the survey questions was to determine common terms used and identify barriers to the use of advanced directives in the nursing homes.

Study Population

The identified participants for this research project

included social workers who currently work in nursing homes in the State of Minnesota. The list of nursing homes was collected from the Minnesota Department of Health web page at the following address: http://www.health.state.mn.us which lists all nursing homes in the state of Minnesota. There were a total of 436 nursing homes in the state, 30 nursing homes were excluded from the study because all the nursing home beds were listed in a hospital setting and may be under different guidelines set by the hospitals. Of the remaining 406 nursing homes, 100 nursing homes were randomly selected and ranged from having 23-300 available beds in the facility. Assumptions about the participants included: their awareness of the terminology of advance directives and the survey content because of the Patient Self-determination Act of 1991, and the knowledge of the requirement of the worker to inform the client of his or her rights regarding advance directives.

The questionnaire included background information that asked for the highest school degree received by each social worker, and how long each worker has been in the current nursing home setting. No names were included on the questionnaire, so anonymity was retained and responses could not be traced to individuals. The questionnaire was mailed to the participants at the nursing home address where they are currently employed. There was no direct contact between the researcher and the participants with the exception of a cover letter that was attached to the questionnaire. The participants were asked to complete the questionnaire within two weeks (See Appendix C)

Data Collection Instruments/Measures

The questionnaire consisted of twelve open-ended and closed-ended questions along with a section for any further comments or suggestions (Appendix C). Participants were asked about any barriers they see with advance directives and the clients they serve. To pretest, the questionnaire was given to two BSW and one MSW nursing home social workers who made recommended changes that were reflected in the survey.

Measurement Error

Systematic error involves the information collected that reflects a false picture of the concepts that are sought to be measured by the way the data is collected (Rubin & Babbie, 1997).

In this research project there was potential for systematic error by possible biases on the questions because of the wording and terms used, or the fact that the questions may not leave room for comments. In the closed-ended questions the participants were only able to respond by picking the answer that is closest to the answer he or she would have chosen if no space for further responses. Systematic error also includes the potential to report what the participant thinks the researcher wants to hear, and not what is accurate in real life. Responses that are not accurate can affect the data collection and results of the study.

Random error has no pattern of inconsistencies, but does relate to the questions in the questionnaire. In this project the random error may include participants finding the study

boring, answering the questions quickly and without much thought due to time constraints, rushing because of the completion deadline. It is also possible that the terminology in the questions may not be readable or is confusing. This could cause participants to guess at the answer he/she thinks is the closest to reality. Random error can be serious as it can reduce the reliability of the study (Rubin & Babbie, 1997).

Level of Measurement and Classification of Variables

The questionnaire was a combination of nominal and ordinal measures that included the following items. Many questions are nominal because they are mutually exclusive and exhaustive due to every answer fitting into a distinct category. Other questions are ordinal in that they are mutually exclusive, exhaustive, and logically ranked in order of the responses. The questions in general are not continuous variables because the responses do not continue to increase over time.

Data Collection Procedures

A cover letter and questionnaire were mailed to each of the randomly selected 100 participants. The cover letter explained the purpose of the research study and instructed the participants on how to complete the questionnaire (Appendix C).

The data collection process included mailing out the surveys with the return deadline of two weeks. Any surveys returned in the two week time frame were included. Once the questionnaires were returned, the researcher calculated the percentage of participant responses to the survey. For the first two questions on the survey the researcher listed a range of responses and in

the data collection added additional categories to calculate the ranges of responses that were not originally on the survey that was sent out to the participants.

Protection of Human Subjects

An application for approval of research was submitted to the Institutional Review Board (IRB) at Augsburg College prior to any contact with human subjects. The IRB approval number is: 99-30-02 (Appendix D).

In order to protect human subjects who participated in the research project, the following steps were taken. The cover letter (Appendix C) explained who the researcher was, the purpose of the research, and how the participants were selected. The participants in the study confirmed his/her consent to participate by completing and returning the survey to the researcher. The participants were assured that completing the survey would not jeopardize his/her job or relation to any professional social work organization. The cover letter also described that there were no direct benefits for the participation in the study and that no financial reimbursement was available for the time it took to complete the survey. Anonymity was stressed with an explanation that the researcher was the only one who has access to the data, and that the data was used only for the study and destroyed once the study was completed.

Data Analysis

The questionnaire included both quantitative and qualitative data. The data was presented in tables, graphs, and narrative

form for appropriate questions. Data was generalized into a summary of the total population in quantitative questions as appropriate.

To analyze the qualitative data the responses were categorized into themes and topics to determine the frequencies of responses in the data and reported using the process of coding and content analysis.

The quantitative method uses tables and graphs to compare responses of participants (Rubin and Babbie, 1997). Since this research study has not been used in the past in regards to social workers' opinions, there are no standard tests or measures to compare the collected data.

Chapter 5

Findings

This chapter presents the results of the study. The findings are organized into sections based on the survey questions looking at results based on the three research questions.

Social Demographics of Study Participants

Of the 100 questionnaires mailed to randomly selected participants 60% (N=60) were returned in the two week time period; all met the study criteria. All of the 60 respondents currently work in nursing homes in the state of Minnesota.

The survey included twelve questions and an area for additional comments and thoughts regarding advanced directives. Respondents (N=60) were asked for their highest college degree earned and 73.3% (n=44) have a Bachelor's degree in Social Work, 6.7% (n=4) have a Master's degree in Social Work, 16.7% (n=10) have other college degrees, and 3.3% (n=2) did not respond to the question. Of the n=10 respondents with other degrees, n=3 are qualified as social service designees and have degrees in nursing, n=6 have Bachelor's degree in sociology, psychology, or gerontology and n=1 participant has a degree as a human service technician. Figure 1 presents the degrees earned by participants.

Figure 1

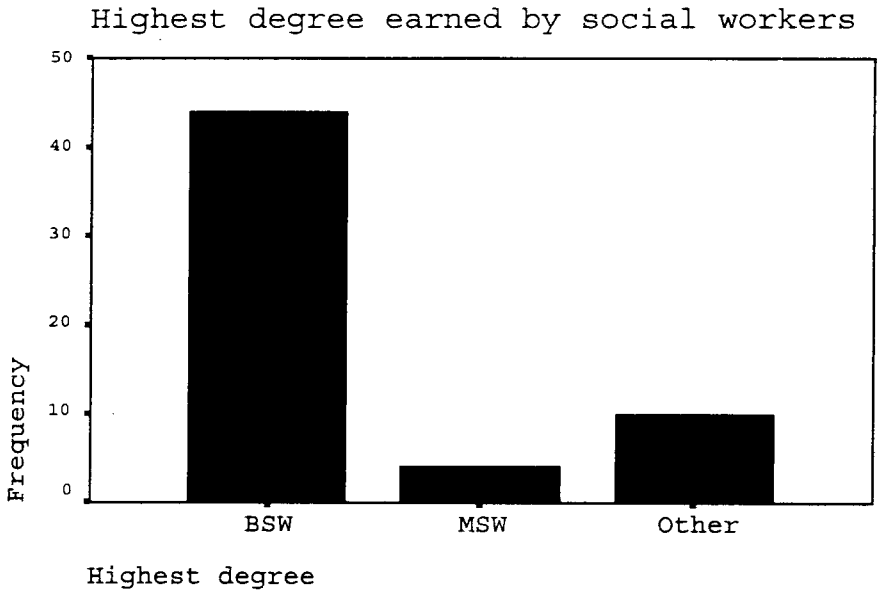

Figure 1. N= 60 respondents, n=44 with BSW degrees, n=4 with MSW degrees, n=10 with other degrees.

The participants were also asked how long they have been working at the current nursing home. The question asked only for the time they have worked in the current nursing home and did not reflect any past experience in nursing home settings. All participants responded to the question (N=60) and the responses were: 5% (n=3) have worked 6 months or less in the nursing home, 31.7% (n=19) between 7 months-3 years, 33.3% (n=20) have 4-9 years experience, 20% (n=12) from 10-15 years, 8.3% (n=5) for 16-25 years experience, 1.7% (n=1) have over 26 years experience. See Figure 2 for the years of employment and experience.

Figure 2

Figure 2. N=60, n=3 worked 6 months or less, n=19 worked 7 months to 3 years, n=20 worked 4 to 9 years, n=12 worked 10 to 15 years, n=5 worked 16 to 25 years, n=1 worked over 26 years in the current nursing home.

When the social workers were asked if they are the persons whom discuss the use of advance directives, 96.7% (N=58) responded that he/she is the main person to discuss the topic. 3.3% (n=2) said it is the resident's doctor who discusses advance directives and they as social workers are secondarily providing further information if requested.

The question further asked for times that the social workers ask residents about advance directives and Table 1 depicts responses to the open-ended question. Some respondents answered

more than one time. There were a total of six different categories of responses. 86.7% (N=52) of social workers responded to the question as being the person to discuss advanced directives and the responses are in Table 1. The table depicts the six responses as: At time of admission to nursing home, at quarterly care conferences held every three months, yearly, as needed or requested by resident or family, a change in medical health or condition, and with resident's doctor.

TABLE 1

When social workers discuss advance directives

Time when discussed	Number of respondents (N=52)
At admission	n= 51 (85%)
Quarterly	n= 16 (26.7%)
Yearly	n= 7 (11.7%)
As needed or requested	n= 15 (25%)
Change in medical health	n= 6 (10%)
With doctor	n= 4 (6.7%)

From this 85% (n=51) of social workers discuss advance directives at the time of admission and many continue to discuss advance directives throughout the time that the resident is in the nursing home. 26.7%(n=16) discuss advance directives every three months at quarterly care conferences, 11.7% (n=7) yearly, 25% (n=15) talk about advanced directives if resident or family request it, 10% (n=6) discuss advance directives when there is a change in the resident's medical condition, and 6.7% (n=4) of social workers discuss advance directives with the residents and

his/her doctor.

Research Question #1

What is the current rate of advance directive use in Minnesota nursing homes by the population age 60 and older?

Participants responded to three questions. Of 60 participants 91.7% (N=55) responded to the question on current census with the numbers ranging from 23-278 beds. 91.7%(N=55) responded to the number of living wills, and 8.3%(n=5) had missing responses to the question. For health care power of attorney, 91.7%(N=55) responded to this question, and 8.3%(n=5) had missing values. Of the 90% (N=54) that responded 10% (n=6) had missing responses. The responses for living will and health care power of attorney available were in ranges of: 0, 1-10, 11-20, 21-30, 31-40, 41-50, 51-60, 61-70, 71-80, 81-90, 91-100, 101-110, 111-120, 121-130, 131-140, 141-150, 151-160, 161-170, 171-180. Originally in the survey the ranges ended at 51 and over and the researcher added the additional ranges to help calculate the percentages and ranges used for table 2. Of the three people who responded with exact numbers for the question on living wills the numbers were: 58 (added to the range 51-60), 81 (added to the range 81-90), and 171 (added to the range 171-180). For the health care power of attorney three people responded with exact numbers of: none had the directive, 41 (added to the range 41-50), 165 (added to the range of 161-170). The range for living will was 885-1380 and 873-1350 for health care power of attorney forms. When the ranges were divided by

the total number of residents (N=5,086) the average of residents in the 55 nursing homes with living wills was 17.4%-27.1%. Of 54 nursing homes that responded to the question on health care power of attorney of N=4,995, 17.5%-27.0% had current health care power of attorney forms. See Table 2 for summary of results.

Table 2

Residents who have advance directives

Advance directive	Total number of nursing home residents	Estimated range of residents with current advance directives	Estimated Percentage of residents with current advance directives
Living will	N=5,086	885-1380	17.4%-27.1%*
Health care power of attorney	N=4,995	873-1350	17.5%-27.0%*

* The total number of nursing home respondents for living wills was N=55 (91.7%) with 5,086 residents in the sample. The total number of nursing home respondents for health care power of attorneys was N=54 (90%) for 4,995 residents included in the sample.

Research Question #2

What are some common barriers to the use of advance directives in nursing homes?

One question on the survey asked about barriers and some reasons residents do not complete advance directives. This question was qualitative for all responses and the following categories of responses emerged from the participants that responded to the question. The total number of participant that responded to the question was 96.7% (N=58).

The categories are:

Impaired cognition and confusion

--Lack of cognitive status and confusion to address topic (n=14)

--No longer able to understand or too ill (n=2)

--Dementia and if he/she completes an advanced directive it means that no care will be given in the dying stage (n=1)

Lack of knowledge about advanced directives

--Lack of knowledge, understanding, and indecisiveness (n=7)

--Lack of education leading to the feeling that children will make poor decisions (n=3)

--Lack of commitment by residents who don't take the time to learn about advanced directives or to discuss them(n=1)

--Lack of assistance by doctors to inform patients about decisions associated with advanced directives (n=1)

Afraid or fear of talking about death and dying

--Afraid to give up control (n=1)

--Complying with societal views on death and dying (n=2)

-- Afraid to bring up topic of death with family members (n=1)

--Not ready to discuss issues regarding directives, denial (n=2)

--Uncomfortable discussing topic with others or doctor (n=1)

--Fears of pain and dying (n=5)

--Fear of one's own mortality (n=2)

Not planning ahead and not feeling sick enough to complete

--Residents do not plan ahead or do not have anyone close to them to help with decisions, or family members do not want the responsibility to make decisions (n=2)

--Residents do not think they need it yet and see it as something to do in the future (n=2)

--Procrastination (n=3)

-- Low motivation to complete forms (n=1)

--Have not completed the forms prior to a significant medical change when it is too late (n=1)

--Stigma of the words "Living Will" (n=1)

--Want family or someone else to make needed decisions (n=5)

Some additional questions asked of the participants involved advance directives as a positive means for stating health care wishes, usefulness of advance directives, and which advance directive is the most effective for nursing home residents.

There was a high response of participants who answered these three questions. 98.3%(N=59) replied about the effectiveness of advance directives with 1.7%(n=1) missing value regarding advance directives, 100%(N=60) for both questions of advance directives as positive means and if they are useful.

The data showed 96.7% (n=58) of participants stated advance directives are a positive means for residents to express their health care decisions and 3.3% (n=2) stated advance directives are sometimes a positive means. Additional comments about the positive means of advanced directives included:

-- No they are not effective as some lawyers write them up and I feel that family members and residents should be the one's to make these decisions (n=1)

-- It helps for residents to express their desires in writing and have some control (n=3)

-- Yes they are effective, but problems arise when family members and doctor's differ in opinions from the resident (n=1)

-- Yes, when physician's follow the advance directives (n=1)

-- It helps to express resident's religious beliefs (n=1)

-- It helps because then families know of wishes (n=5)

-- Yes, but it should be completed earlier in life when cognition is more intact (n=1)

-- Yes, but many residents do not put specific instructions on the documents and not always possible to predict all health care situations (n=1)

Figure 3 depicts the responses of the participants regarding advance directives as positive health care decision-making tools.

Figure 3

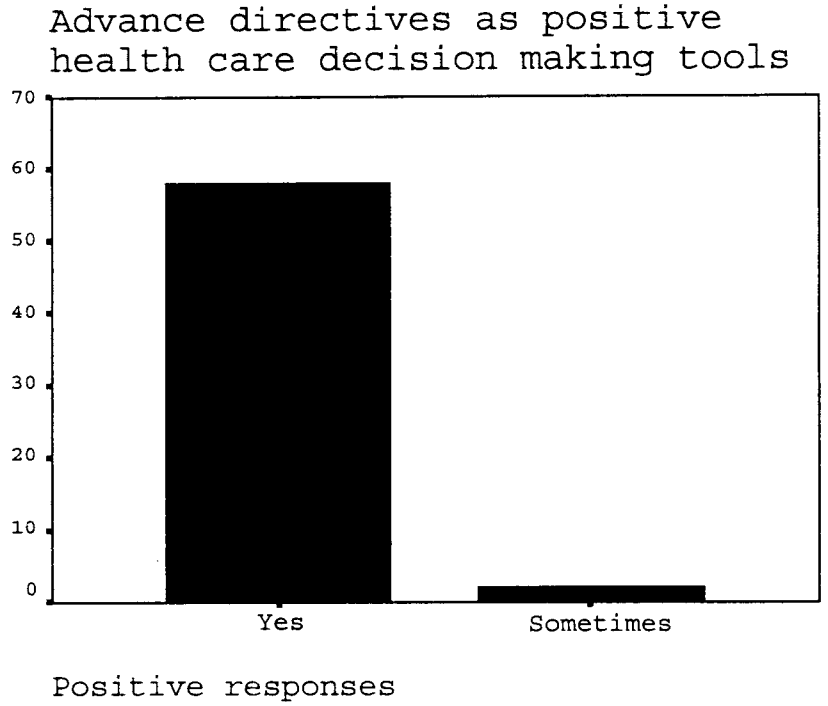

Figure 3. N=60, n=58 said yes and n=2 said sometimes.

For the question regarding the usefulness of advance directives 90%(n=54) stated they are useful, 1.7% (n=1) stated they are not

useful, and 8.3% (n=5) stated they are sometimes useful. Participants expanded on this question with the following written statements:

--Yes, but the way they are implemented is too confusing for the elderly (n=1)

-- They serve as a guide when used appropriately (n=2)

-- Yes, particularly regarding artificial nutrition decisions and hospitalization (n=2)

-- Good unless the family does not honor the decisions(n=1)

-- Yes and it would be great if more people completed them (n=1)

-- Yes as it may be the first time the resident is able to discuss death and the dying process with others (n=1)

-- It helps because many family members live far away and it it gives the facility a plan of what to do with health changes (n=1)

-- It is easy to follow especially if resident has a large family who have differing opinions (n=1)

-- Helps health care staff and families to know wishes (n=5)

-- It shows the resident has been giving the topic some thought on this sensitive issue (n=1)

Figure 4 depicts the responses for the question of usefulness of advance directives.

Figure 4

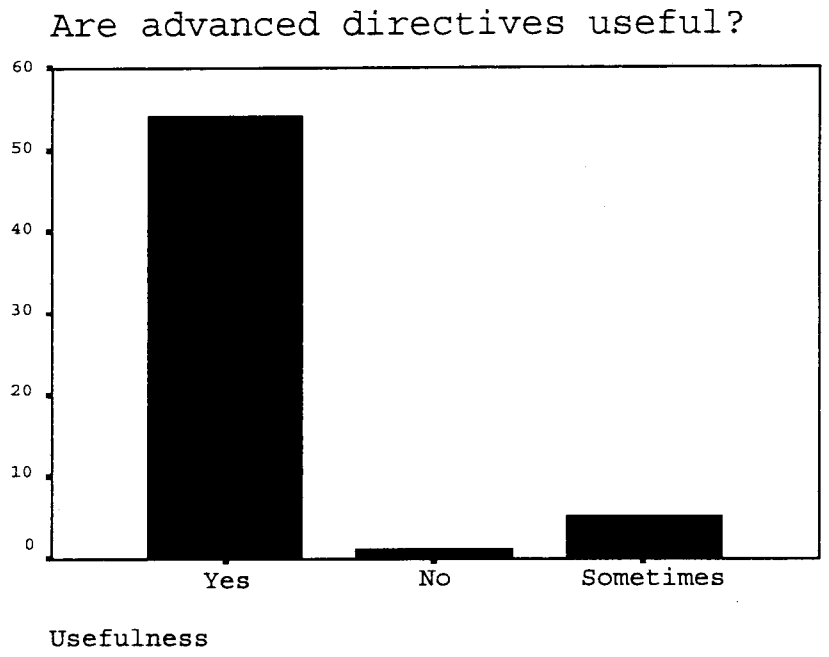

Figure 4. N=60 respondents, n=54 said yes, n=1 said no, n=5 said sometimes advance directives are useful.

The third question asked the participants which advance directive is most effective and gave four response options of: living will, health care power of attorney, both, or neither. 98.3% (N=59) responded to this question. 1.7% (n=1) stated that the living will is most effective, 45% (n=27) stated health care power of attorney is most effective, 43.3% (n=26) stated both of these advance directives are effective, and 8.3% (n=5) stated that neither of the forms are effective.

Additional comments by participants were:

--Situations change day to day with the elderly population

(n=1)

--Health Care Power of Attorney form is easier to understand (n=4)

--The new Health Care Directive form is a big improvement (n=13)

--The Living Will form is too complicated and subject to interpretations by people (n=3)

--The forms are more effective when family is involved (n=1)

See Figure 5 for graph of responses on most effective advance directive as noted by participants.

Figure 5

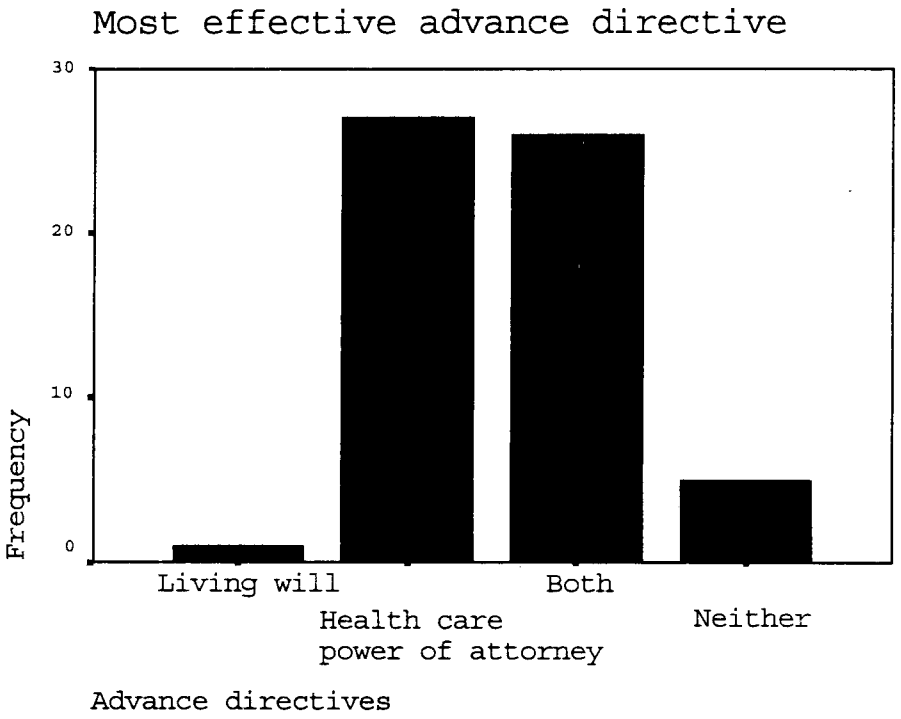

Figure 5. N= 59, n=1 said living will, n=27 said health care power of attorney, n=26 said both are effective, n=5 said neither forms are effective.

Another question asked participants if advance directives are understandable by residents in the nursing home. 98.3%(N=59) participants responded in qualitative responses as follows:

--Residents do not always understand, not 100% because of cognitive impairment (n=27)

--Yes, residents do understand advanced directives (n=13)

--Wording is too difficult and not easy to understand (n=1)

--Understandable when discussed with social worker(n=3)

--No, not for those with dementia (n=2)

--No, residents do not understand advanced directives (n=13)

Research Question #3

Do nursing home social workers perceive they have adequate information and training to educate the elderly population about advance directives?

Two questions on the survey asked participants if they had received training on advance directives, and if they think they had adequate training on advance directives. The questions were both quantitative and qualitative. All participants responded (N=60) and the responses were: 86.7% (n=52) of participants had received training on advance directives, 11.7% (n=7) stated no they have not had any training, and 1.7% (n=1) did not respond to the question. 95% (N=57) responded to the second question about participants receiving adequate training and responses were: 18.3% (n=11) said no they do not have adequate training and 76.7% (n=46) feel they do have adequate training. See Figures 6 and 7 for graph of responses on the two questions

regarding training and advance directives.

Figure 6

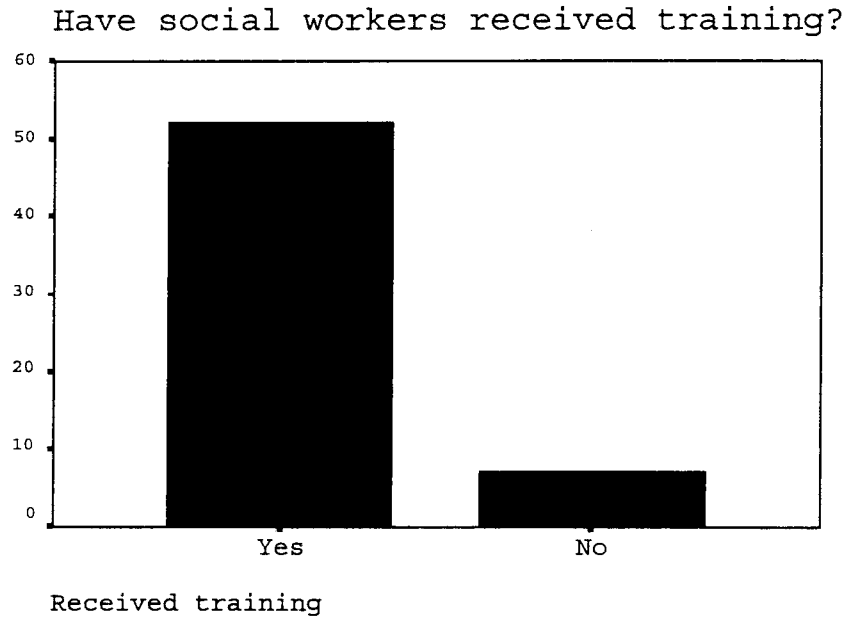

Figure 6. N= 60, n=52 have received training, n=7 have not had training, n=1 missing values.

Figure 7

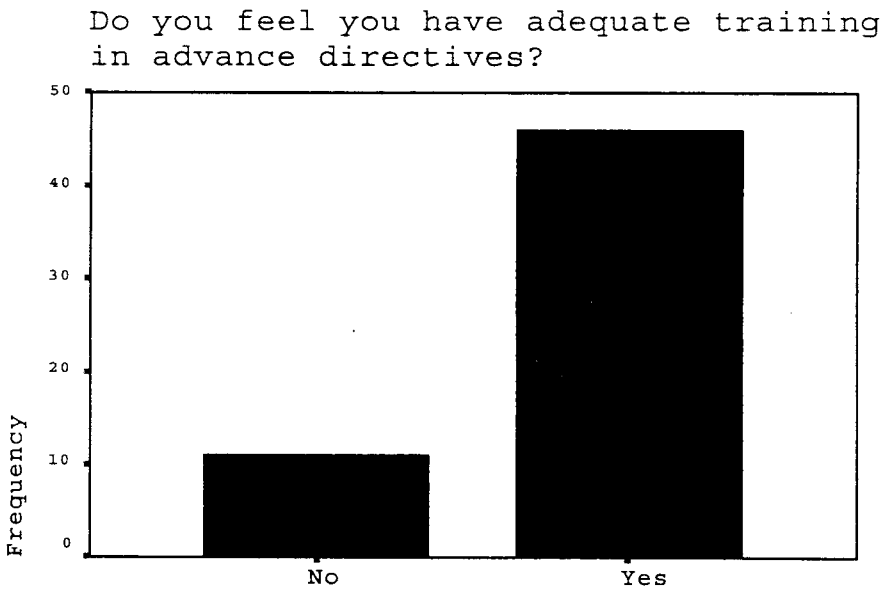

Figure 7. N=57 total respondents, n=11 said they did not have adequate training, n=46 said they had adequate training on advance directives.

Some participants also responded to the questions in writing pertaining to training they received. For the question have you received any training additional comments were:

--Yes, the class was about discussions of legal aspects and state law changes (n=12)

--Yes, classes on the new Minnesota Health Care Directive (n=5)

--Yes, participant took a refresher class on advanced directives (n=5)

--Yes the class was on practical ideas and ways to help families and residents to discuss advance directives (n=4)

--Yes, the class was to help train social workers to teach others about advance directives (n=2)

An additional n=4 responded that they have not had any training recently on advance directives.

For the question about adequate training comments were:

--No, more training and information is needed because of legalities (n=2)

--Can use more training on medical questions and definitions to help explain terms on the forms (n=3)

--Refer to the resident's doctor if unsure of questions or understanding (n=4).

--Refer to the nurse if additional questions (n=1)

--Hard to know what to do if residents want social worker to make decisions for them (n=1)

--With the new law changes effective August 1998, more training is needed (n=2)

Many also commented that the reason they are comfortable discussing advance directives is from years of experience in the nursing homes.

The last part of the survey gave participants a chance to express comments or thoughts regarding the survey and/or on advance directives. Four main categories emerged following the study and the categories of responses included:

Completing advance directives before entering the nursing home

--Families should encourage their parents to complete advance directives before entering the nursing home (n=1)

--Need to have people complete the forms more in advance (n=1)

--Middle age people should execute health care directives and change the forms later in life as needed while they are still cognitively able to understand the forms (n=1)

--"I want people to be educated on advance directives and to know that attorneys are not the best people to do the forms as this is a common misconception" (n=1)

Understanding of advance directives

--People don't fully understand the forms (n=1)

--There is confusion with some resident's families who think a financial power of attorney form can be used for health care decisions (n=1)

The new Minnesota Health Care Directive

--"The new health care directive is more acceptable and I support the changes in the law" (n=1)

--"Advance directives and resident wishes are often the last thing thought of by families and physicians. The new directive forms are worthless as many leave the questions blank" (n=1)

--"The new terminology is health care directive that combines the two forms and you did not ask me about this-why?" (n=1)

--The new law change effective August of 1998 has been a great change" (n=1)

--"In our facility when the new law on advance directives went into play we disposed of all old forms and changed to the new forms" (n=1)

Additional comments

--"I found a tool put out by MN extension service from the University of Minnesota entitled 'Life and death health care decisions: Sorting out preferences' as helpful when discussing advance directives" (n=1)

--"Advance directives do not have an easy explanation as there are too many variables for elderly people to deal with. It needs to be simplified" (n=1)

--"I don't think any social worker or nurse can adequately take the role of discussing advance directives. It should be discussed by the physician because he has the medical background" (n=1)

--"It is clear that some people don't want to make these decisions and are uncomfortable with discussion of dying. Some residents stay full-code even with a terminal illness" (n=1)

--"I have seen that some physicians are reluctant to discuss living wills and refer to the facility to discuss advance directives" (n=1)

See Appendix E for a copy of the new Health Care Directive form that was discussed in the additional comments by many of the participants.

Chapter 6

Discussion

This study summarized responses of nursing home social workers in regard to the use of advance directives by residents in nursing homes in the state of Minnesota. This chapter summarizes the data findings and relates them to the literature review and theories from chapters 2 and 3. In addition, the strengths and limits of the study, implications for social work, and future research suggestions pertaining to advance directives are discussed.

Relevance to Research Questions

The three research questions that the survey was designed to answer are as follows:

What is the current rate of advance directive use in Minnesota nursing homes by the population age 60 and over?

What are some barriers to the use of advance directives in nursing homes?

Do nursing home social workers in Minnesota perceive they have adequate information and training to educate the elderly population about advance directives?

Before looking at each of these questions the data collected also included some background information about the social workers that is important to discuss. Social workers were to respond to what is the highest degree they have earned, how long he/she has worked in the current nursing home setting, and when they discuss advance directives with residents. Of social

workers who responded, 80% (n=48) had a Bachelor's or Master's degree in social work.

The second part shows that 63.3% (n=38) of the social workers have been working as a social worker in the current nursing home from 4 years to over 26 years. And 31.7% (n=19) have been in the settings for 7 months to 3 years. Only 5% (n=3) of respondents have been in the current nursing home for less than 6 months. This is important data because many social workers commented that their knowledge of advance directives came with years of experience and opportunities to receive training on advance directives.

Diamond (1989) noted that when elderly patients were given an advance directive form without further discussion, they do not understand the form and were confused by the information. The research study discusses this as many social workers perceive the need to talk to residents about advance directives beyond admission. Because of the circumstance of admission to the nursing home as being stressful and overwhelming without adding the topic of advance directives many social workers saw residents as not understanding the directives unless the topic was discussed further beyond the time of admission. The data shows that 85% (n=51) of social workers discuss advance directives at the time of admission. Table 1 also shows that social workers discuss advanced directives at quarterly care conferences, yearly, and many other times throughout the resident's stay at the nursing home. This shows that the social workers are aware that admission is not the only time for

discussion and that the topic of advance directives needs to be addressed frequently.

Research Question #1

Regarding the first research question on the current rate of use of advance directives in nursing homes, the data shows some important findings related to the literature review. The percentages of residents in the nursing homes using advance directives varies greatly on both the use of living will and health care power of attorney forms within each nursing home. Some responded that none of the residents had health care power of attorney forms, and others responded that 100% of the residents had these directives. It should be noted that residents can have both a living will and health care power of attorney forms completed which is accounted for in both groups of responses.

As earlier noted in the introduction and literature review, people over the age of sixty-five account for 73% of deaths in the United States and 30% of these people do not have someone to help them with health care decisions (Haynor, 1998). The literature review indicated that even with the Federal Patient Self-Determination Act of 1990 in place only 5%-17.5% of people have completed advance directives (Sansone, 1995). Of the social workers that responded to the questions on the survey (N=55) the average of people over the age of 60 who completed living wills ranged from 17.4%-27.1% and 17.5%-27.0% for health care power of attorney forms. The percentages from the sample group are at the higher end of the range in comparison to the range of 5%-17.5%

states by Sansone (1995) for completed advance directives.

There were nursing homes that had a larger number of residents with advance directives and many social workers continue to discuss advance directives with new residents entering the nursing homes. It should be noted that in the research study the researcher added additional ranges of responses to calculate the ranges that affected the responses of three people for living will and 2 people for health care power of attorney. Adding these additional groups can affect the results slightly in accordance to calculating the range of responses. The researcher felt it was important to include these responses in the data results as the numbers reflect responses from larger nursing homes. From this research social workers perceive that advance directives continue to be completed by the elderly population in Minnesota nursing homes at a slightly higher rate than reported in literature review.

Research Question #2

The second research question discusses some barriers to the use of advance directives. On the survey the question was qualitative and many respondents gave barriers to advance directives that they have seen from the residents they work with in the nursing home. The following four categories summarize the data: Impaired cognition and confusion, lack of knowledge, fear of talking about death, and not planning ahead.

In chapter 2 there was a noted study by Kirmse (1998) that talked about ten common barriers. Of those ten barriers this study shows that social workers are seeing six in the nursing

home setting. The six common responses that Kirmse (1998) stated are: procrastination, dependence on family members to make decisions, lack of knowledge about advance directives, difficulty with discussing the topic, fatalism, and fear of not being treated for any medical needs if an advance directive is in place. This study supports these findings.

Three additional questions asked social workers about advance directives being useful, effective, and seen as a positive means to make wishes known. It was surprising to note that social workers responded favorably to all of these questions and stated that advance directives are effective for nursing home residents. 90% (n=54) of social workers stated advance directives are useful and only 1.7% (n=1) stated the directives are not useful. Additional responses indicated that directives serve as a guide and many wished more people would use advance directives. 96.7% (n=58) of respondents stated that advance directives are a positive means to express health care decisions and give the resident, family members, and nursing home staff a plan to follow if the resident is unable to express his/her needs.

The third question asked respondents which advance directive is most effective and many respondents commented that health care power of attorney alone (45%, n=27) or both forms together (43.3%, n=26) are most effective. One comment that was noted in the survey is that the researcher did not ask about the new health care directive that was recently implemented in August of 1998. Some respondents (n=3) see the new form of the combination

of the living will and health care power of attorney forms as an improvement.

The literature review stated there are drawbacks and strengths to both advance directive forms. A strength of a living will is the opportunity to write down one's own wishes and it gives people a sense of control over end-of-life care (Robertson, 1991). Drawbacks are that many elderly people have a fear about the topic of death and that advance directives are only effective in terminal stages (Galambos, 1989).

A strength of the health care power of attorney is increased flexibility of use and provides the opportunity for the involvement of another person to help with decisions (Pellegrino, 1992). A drawback is that the person designated to make decisions may not make the same choices the patient would make especially if it involves withdrawing life-sustaining treatments (Emanuel, 1991).

Research Question #3

The third research question focuses on training and education that social workers have to educate nursing home residents. The researcher was expecting that fewer social workers would have stated that they had a full understanding of advance directives. The data shows that 86.7% (n=52) of social workers have had some training or class on advance directives which verifies that training is available to social workers. 76.7% (n=46), stated they feel they have adequate training on advance directives. This question also had a place to respond in writing and even though many stated that they have adequate

training, some said a refresher class about the state laws and medical terminology would be helpful.

At the end of the survey social workers were given the opportunity to comment on the questions in the survey and on advanced directives. Some important responses included: Families should encourage people to complete advance directives before entering the nursing home, advance directives do not have an easy explanation and need to be simplified, and many elderly people are still not ready to discuss the topic of death and dying.

Comparison of Findings to Theoretical Framework

As discussed earlier in chapter 3, the theories related to advance directives look at increasing a person's autonomy and control over decisions in health care. The *ecological theory* relates to how people interact with their environment, family roles, and boundaries. This theory relates to the survey findings by stating that advance directives can assist in decreasing the stresses on a person who has the directive in place before other health conditions change (Germain, 1980).

The *ego theory of psychology* relates to the research findings through the focus on defense and denial. The research conclusions noted that social workers perceive that many of the nursing home residents have a fear of death and deny their own mortality. This theory helps to explain some of the common barriers that were noted in the data collection of why advance directives are not completed (Turner, 1986). Denying one's own mortality is a coping mechanism for many of the nursing home

residents who distance themselves from the reality that they are not going to live forever. Denying mortality relates to the barriers of fear of completing advanced directives and not being able to think ahead to future health changes (Galambos, 1989).

The third theory *narrative theory of personhood* relates to the autonomy of the individual and decision-making capabilities and states that a person's decisions should be considered when new situations arise. Using advance directives would increase the patient's autonomy and reflect the person's past physical and mental states when the directive was completed. The family and others must account for the person's past mental state and not the current mental state if the person has developed dementia or become confused. The key to the theory is to recognize the person as an individual and look at past interests and values of the person (Tonelli, 1996). In the research one social worker said that people should complete advance directives in their 50's or earlier before he/she becomes confused or unable to make decisions and this reflects the theory of looking at the past status of the person and his/her life. Other social workers stated that people should complete the forms earlier in life and make health care decisions known to family members and his/her doctor to remain autonomous in the later years of life.

Strengths of Study

A strength to this research project is there have not been other studies that look at the opinion of the social workers directly involved with the clients who are potential benefactors

of advance directives. This study also has the benefit of targeting a group of social workers that is familiar with the terms and forms available for advance directives. Due to the use of professional social workers versus direct clients, the return rate of the surveys was potentially higher. The survey was sent by mail and self-administered so that the participant could complete it at a convenient time.

Limitations to the Study

Some limitations of the survey questionnaire are the questions and design of the survey were tested only one a small sample of social workers and the survey was designed by the researcher and not a standardized test. Another limitation was the survey was short and could have been too vague to adequately cover the topic of advance directives. A questionnaire with poor wording and potentially leading questions can limit the accuracy and true feelings of the participants. Many questions are quantitative and not very flexible which limits personal thought. The researcher also added additional responses to questions 1 and 2 to calculate the ranges of responses that were not originally included in the survey that can effect the results of the numbers reported in Table 2 for survey results.

Implications for Social Work Practice

On an individual level, health care social workers can use the data to assist with the dissemination of information to clients about advance directives. The study directly relates to the important concepts in social work including autonomy and decision-making and how these concepts are related to the

elderly population through use of advance directives.

On the larger level of social work practice, this research provides helpful insight to other social workers working with the elderly population. The data can also be used to highlight some barriers to advance directives as social workers surveyed perceive that advance directives are a difficult topic for many elderly people to talk about. Also the data indicates that social workers need to discuss advanced directives often with elderly people.

This study also shows that the Federal Patient Self-Determination Act of 1991 still has a long way to go to increase the use of advance directives and health care decisions. One of the main purposes of the Act was to educate elderly populations about advance directives. The study shows that even when the topic is discussed people may still not complete the forms. With the new Health Care Directive that went into effect in the State of Minnesota in August of 1998, many social workers are still learning more about advance directives and many social workers outside of nursing homes may not be aware of the law changes.

Conclusion and Recommendations for Future Research

This research study was designed to identify some common barriers to advance directives and to gather the thoughts of nursing home social workers who daily work with the elderly population. Results of the survey indicate that there are still barriers and plenty of room for growth in the area of educating elderly about advance directives and having families and doctors more involved in the process.

One additional area noted by participants was that the researcher did not talk about the new Health Care Directive that was effective August 1998. The researcher is aware of this new state law change and chose not to discuss it since there has not been enough time to implement the changes. Many participants talked about the new Health Care Directive and many liked the form better than the two separate forms of living will and health care power of attorney.

Overall, the research showed by the high response rate of the survey that the topic is important to social workers and many stated there is room for improvement and more education is needed about advance directives.

Future research could expand to a larger population of social workers who work with the elderly population in many settings, not only in nursing homes. The survey could expand into other states and use interviews or a survey with more questions about advance directives and new law changes.

One difficulty with the study of advance directives is that each state has different forms and laws regarding advance directives. Future research could also expand to include more research on cultural group and different races as some literature has noted that differences do occur with advance directive use. As more people continue to reach retirement age it is important to continue to discuss advance directives and give people the opportunity to express their health care needs.

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APPENDICES

APPENDIX A

LIVING WILL FORM

Source: Minnesota Board On Aging, 1996

MINNESOTA HEALTH CARE DECLARATION (LIVING WILL)

Name _____

Address: _____

Telephone: _____ Birthdate: _____

NOTICE: THIS IS AN IMPORTANT LEGAL DOCUMENT. BEFORE SIGNING THIS DOCUMENT, YOU SHOULD KNOW THESE IMPORTANT FACTS:

(A) This document gives your health care providers or your designated proxy the power and guidance to make health care decisions according to your wishes when you are in a terminal condition and cannot do so. This document may include what kind of treatment you want or do not want and under what circumstances you want these decisions to be made. You may state where you want or do not want to receive any treatment.

(B) If you name a proxy in this document and that person agrees to serve as your proxy, that person has a duty to act consistently with your wishes. If the proxy does not know your wishes, the proxy has the duty to act in your best interests. If you do not name a proxy, your health care providers have a duty to act consistently with your instructions or tell you that they are unwilling to do so.

(C) This document will remain valid and in effect until and unless you amend or revoke it. Review this document periodically to make sure it continues to reflect your preferences. You may amend or revoke this declaration at any time by notifying your health care providers.

(D) Your named proxy has the same right as you have to examine your medical records and to consent to their disclosure for purposes related to your health care or insurance unless you limit this right in this document.

(E) If there is anything in this document that you do not understand, you should ask for professional help to have it explained to you.

TO MY FAMILY, DOCTORS, AND ALL THOSE CONCERNED WITH MY CARE:

I, _____, born on _____(birthdate) being an adult of sound mind, willfully and voluntarily make this statement as a directive to be followed if I am in a terminal condition and become unable to participate in decisions regarding my health care. I understand that my health care providers are legally bound to act consistently with my wishes, within the limits of reasonable medical practice and other applicable law. I also understand that I have the right to make medical and health care decisions for myself as long as I am able to do so and to revoke this declaration at any time.

(1) The following are my feelings and wishes regarding my health care (you may state the circumstances under which this declaration applies):

_____

_____

(2) I particularly want to have all appropriate health care that will help in the following ways (you may give instructions for care you want):

_____

_____

(3) I particularly do not want the following (you may list specific treatment you do not want in certain circumstances):

_____

(4) I particularly want to have the following kinds of life-sustaining treatment if I am diagnosed to have a terminal condition (you may list the specific types of life-sustaining treatment that you do want if you have a terminal condition):

_____

_____

(5) I particularly do not want the following kinds of life-sustaining treatment if I am diagnosed to have a terminal condition (you may list the specific types of life-sustaining treatment that you do not want if you have a terminal condition):

_____

_____

(6) I recognize that if I reject artificially administered sustenance, then I may die of dehydration or malnutrition rather than from my illness or injury. The following are my feelings and wishes regarding artificially administered sustenance should I have a terminal condition (you may indicate whether you wish to receive food and fluids given to you in some other way than by mouth if you have a terminal condition):

_____

_____

(7) Thoughts I feel are relevant to my instructions (you may, but need not, give your religious beliefs, philosophy or other personal values that you feel are important. You may also state preferences concerning the location of your care.):

_____

_____

(8) Proxy Designation. (If you wish, you may name someone to see that your wishes are carried out, but you do not have to do this. You may also name a proxy without including specific instructions regarding your care. If you name a proxy, you should discuss your wishes with that person.)

If I become unable to communicate my instructions, I designate the following person(s) to act on my behalf consistently with my instructions, if any, as stated in this document. Unless I write instructions that limit my proxy's authority, my proxy has full power and authority to make health care decisions for me. If a guardian or conservator of the person is to be appointed for me, I nominate my proxy named in this document to act as guardian or conservator of my person.

Name: _____

Address: _____

Telephone No.: _____ Relationship (if any) _____

If the person I have named above refuses or is unable or unavailable to act on my behalf, or if I revoke that person's authority to act as my proxy, I authorize the following person to do so:

Name: _____

Address: _____

Telephone No.: _____ Relationship (if any) _____

I understand that I have the right to revoke the appointment of the persons named above to act on my behalf at any time by communicating that decision to the proxy or my health

ORGAN DONATION AFTER DEATH

(If you wish, you may indicate whether you want to be an organ donor upon your death.)

Initial the statement which expresses your wish:

_____ In the event of my death, I would like to donate my organs. I understand that to become an organ donor, I must be declared brain dead. My organ function may be maintained artificially on a breathing machine, (i.e., artificial ventilation), so that my organs can be removed.

Limitations or special wishes: (If any) _____

I understand that, upon my death, my next of kin may be asked permission for donation. Therefore, it is in my best interest to inform my next of kin about my decision ahead of time and ask them to honor my request.

I (have) (have not) agreed in another document or on another form to donate some or all of my organs when I die.

_____ I do not wish to become an organ donor upon my death.

DECLARANT SIGNATURE

SIGNED_____ DATE_____

NOTARY

STATE OF _____ COUNTY OF _____

Subscribed, sworn to, and acknowledged before me by: _____

on this _____day of_____,19 _____

Notary Public_____

-OR-

WITNESS SIGNATURES

(Sign and date here in the presence of two adult witnesses, neither of whom is entitled to any part of your estate under a will or by operation of law, and neither of whom is your proxy.)

I certify that the declarant voluntarily signed this declaration in my presence and that the declarant is personally known to me. I am not named as a proxy by the declaration, and to the best of my knowledge, I am not entitled to any part of the estate of the declarant under a will or by operation of law.

WITNESS _____

ADDRESS _____

WITNESS _____

ADDRESS _____

REMINDER: Keep the signed original with your personal papers. Give signed copies to your doctors, family, and proxy.

APPENDIX B

HEALTH CARE POWER OF ATTORNEY FORM

Source: Minnesota Board On Aging, 1996

MINNESOTA HEALTH CARE POWER OF ATTORNEY

I, _____
(Name and Address of Principal)
appoint as my attorney-in-fact (hereafter referred to as "Agent")

_____
(Name and Address of Agent)
to make any health care decision for me when, in the judgement of my attending physician, I am unable to make or communicate the decision myself and my agent consents to make or communicate the decision on my behalf.

My agent has the power to make any health care decision for me. This power includes the power to give consent, to refuse consent, or to withdraw consent to any care, treatment, service, or procedure to maintain, diagnose, or treat my physical or mental condition, including giving me food or water by artificial means. My agent has the power, where consistent with the laws of Minnesota, to make a health care decision to withhold or stop health care necessary to keep me alive. It is my intention that my agent or any alternative agent has a personal obligation to me to make health care decisions for me consistent with my expressed wishes. I understand, however, that my agent or any alternative agent has no legal duty to act.

My agent and any alternative agents have consented to act as my agent: My agent and any alternative agents have been notified that they will be nominated as a guardian or conservator for me.

My agent must act consistently with my desires as stated in this document or as otherwise made known by me to my agent.

My agent has the same right as I would have to receive, review, and obtain copies of my medical records and to consent to disclosure of those records.

DESIGNATION OF ALTERNATE AGENT (OPTIONAL)

(You are not required to designate one or more alternate agents, but you may do so. An alternate agent may make the same health care decisions as your designated agent, if the designated agent is unable or unwilling to act as your agent.)

If my agent named by me shall die, become legally disabled, incapacitated or incompetent, or resign, refuse to act, or be unavailable, I name the following (each to act successively in the order named) as my alternate agent.

First Alternate Agent

Name: _____

Address: _____

Second Alternate Agent

Name: _____

Address: _____

SPECIAL INSTRUCTIONS (OPTIONAL)

(You may give your agents any special instructions in this section. If you do not wish to do so, put "None" on the line provided.)

_____

LIMITATIONS (OPTIONAL)

(You may wish to put additional limitations on your agents in this section. If you do not wish to do so, put "None" on the line.)

_____

ORGAN DONATION AFTER DEATH

(If you wish, you may indicate whether you want to be an organ donor upon your death.)

Initial the statement which expresses your wish:

_____ In the event of my death, I would like to donate my organs. I understand that to become an organ donor, I must be declared brain dead. My organ function may be maintained artificially on a breathing machine, (i.e., artificial ventilation), so that my organs can be removed.

Limitations or special wishes: (If any) _____

I understand that, upon my death, my Agent(s) named in this document may be asked permission for donation. Therefore, it is in my best interest to inform my Agent(s) about my decision ahead of time and ask him/her to honor my request.

I (have) (have not) agreed in another document or on another form to donate some or all of my organs when I die.

_____ I do not wish to become an organ donor upon my death.

OTHER PROVISIONS

I revoke any prior Health Care Power of Attorney.

I understand that I may revoke this Health Care Power of Attorney at any time.

This Health Care Power of Attorney is intended to be valid in any jurisdiction in which it is presented.

This Health Care Power of Attorney shall become effective upon my disability or incapacity.

Photocopies of this Health Care Power of Attorney may be relied upon as originals.

SIGNATURE OF PRINCIPAL

I am fully informed as to all the contents of this Health Care Power of Attorney and understand the full import of this grant of power to my agent(s). I further declare that I am emotionally and mentally competent to make this Health Care Power of Attorney.

_____ _____

(Signature of Principal) (Date)

WITNESS STATEMENT

I declare under penalty of perjury under the laws of the State of Minnesota that the person who signed this document is personally known to me to be the Principal; that the Principal signed this document in my presence; or directed another person to sign this document on his behalf in my presence; that I have signed this document in the presence of the Principal and also in the presence of the other witness; that the Principal appears to be of sound mind and under no duress, fraud, or undue influence; that I am 18 years of age or older; and I am not the person appointed as agent or alternate agent in this document.

_____ _____

(First Witness Signature) (Address)

_____ _____

(Second Witness Signature) (Address)

ADDITIONAL WITNESS STATEMENT

(At least one of the witnesses must sign this additional statement.)

I declare under penalty of perjury under the laws of the State of Minnesota that I am not a health care provider providing direct care to the Principal, or an employee of a health care provider providing direct care to the Principal on the date of execution of this document.

_____ _____

(Witness Signature) (Address)

NOTARY PUBLIC

(You may sign this document in front of a notary, instead of having it witnessed.)

State of Minnesota)
) ss.
County of)

On this_____day of _____, in the year_____ before me, the undersigned, a Notary Public in and for the state of Minnesota personally appeared _____(the Principal) personally known to me (or proved to me on the basis of satisfactory evidence) to be the person whose name is subscribed to this instrument; and acknowledged that he or she executed it as his or her voluntary act or deed.

I declare under penalty of perjury that the person whose name is subscribed to this instrument appears to be of sound mind and under no duress, fraud or undue influence, and that I am satisfied as to the genuineness and due execution of this document.

I also declare that I am not the agent or alternate agent appointed in this document.

(NOTARY SEAL)

_____

Signature of Notary

APPENDIX C

COVER LETTER AND SURVEY

March 31, 1999

Dear (Director of Social Services),

I am pursuing my graduate degree in social work at Augsburg College in Minneapolis, Minnesota and currently working on my thesis. As a part of the Master's degree in the social work program, I am conducting a research project on the current use of advanced directives in nursing home settings in Minnesota.

The purpose of this research study is to examine the use of advanced directives in nursing home settings, as directly observed by social workers throughout the state of Minnesota. This research will explore health care social workers' perceptions and use of advanced directives with clients who are sixty years old or older.

The Internet web site of the Minnesota Department of Health lists all Minnesota nursing homes and your nursing home has been randomly selected to participate in this study. Your opinion and time are important and your participation is entirely voluntary. Your participation will allow the researcher to gather more data about the use and potential barriers of advanced directives and also if social workers perceive they have adequate training and knowledge to help residents complete advanced directives.

The research questionnaire consists of twelve questions about advanced directives in nursing home settings and will take approximately fifteen minutes to complete. This is a one-time questionnaire to complete and please do not place your name or any other identifying information on the questionnaire, as all participants will remain anonymous. Completion and return of this survey by April 14, 1999 will indicate your consent to participate in the study.

Your decision whether or not to participate in this study will not affect any current or future relationship with your place of employment or Augsburg College.

IRB# 99-30-02

You may skip any questions that you feel uncomfortable answering without the consequence of dropping out of the whole study. Only the researcher and my thesis advisor will have access to this data and the data will be kept in a locked box in the researcher's home and destroyed by September 30, 1999.

Please read through the questions carefully and return the questionnaire in the enclosed stamped self-addressed envelope.

Please return by April 14,1999

Thank you for your cooperation and assistance. If you have any questions please contact my thesis advisor, Dr. Sharon Patten: (612) 330-1723 or my pager # (612) 640-3252.

Sincerely,

Denise Sigstad LSW
MSW Student-Augsburg College
Campus Mailbox # 409
Augsburg College
2211 Riverside Ave.
Minneapolis, MN 55454

IRB# 99-30-02

Instructions

Most of the questions can be answered by circling the response that reflects your perspective. If the question includes the choice of other, please remember to specify what other means. At the end of the questions there is a space for other comments regarding the study. Please feel free to comment about the project or the topic discussed.

Please recall that the questions focus on clients who are in the age group of being sixty years old or older. The questionnaire is to be based on your current census in the nursing home.

Once again thank you for your participation.

Questionnaire on the use of advanced directives

1. Of the current residents who have completed advanced directives how many in your facility have living wills?
   A.none D. 21-30
   B. 1-10 E. 31-40
   C. 11-20 F. 41-50
   G. 51 or over, please specify number _____

2. How many current residents have completed Durable Health Care Power of Attorney (Health Care POA)?
   A. None D. 21-30
   B. 1-10 E. 31-40
   C. 11-20 F. 41-50
   G. 51 or over, please specify number _____

3. Are you the person in the facility who discusses advanced directives with the residents?
   A. Yes
   B. No
   If yes, when do you discuss advanced directives?
   _____
   _____

4. Do you feel residents at the nursing home understand advanced directives? _____
   _____

5. Which do you feel is more effective for residents?
   A. Living Will
   B. Health Care Power of Attorney
   C. Both
   D. Neither
   Please explain _____

6. Do you see advanced directives as a positive means for residents to express their health care decisions?
   _____
   _____

7. What are some common barriers or reasons residents do not complete advanced directives?
   _____
   _____
   _____

8. From your perspective, are advanced directives useful?
   _____
   _____

The following questions are for background information.

9. How long have you worked in this nursing home?
   A.6 months or less
   B.7 months-3 years
   C. 4-9 years
   D. 10-15 years
   E. 16-25 years
   F. over 26 years How many? ___

10. What is the highest degree you have received?
   A. BSW
   B. MSW
   C. Other degree, please specify:
   _____

IRB# 99-30-02

11. Have you received any training or attended any educational seminars regarding advanced directives?
    A. Yes
    B. No
    If yes, what was helpful about the training?
    _____

12. Do you feel you have adequate training to discuss advanced directives with residents?
    _____
    _____

The Department of Health has listed your facility to have _____ number of nursing home beds. Please specify what your current census is at the time of filling out this survey _____

Any additional comments or thoughts regarding the survey or advanced directives:_____
_____
_____

Thank you for your cooperation it is greatly appreciated. Please return the survey by April 14, 1999 in the enclosed self-addressed envelope.

IRB# 99-30-02

APPENDIX D

IRB APPROVAL LETTER

MEMO

April 7, 1999

TO: Ms. Denise Sigstad

FROM: Dr. Lucie Ferrell, IRB Chair

RE: Your IRB Application

I am writing to confirm our telephone conversation that you have met the conditions of IRB approval, and your study, "The Study of the Use of Advanced Directives in MN Nursing Homes," is approved, IRB approval number 99-30-2. Please use this number on all official correspondence and written materials relative to your study. For your college post office box, please contact Ms. Shawn Postera at 612-330-1119.

Your research should prove interesting and very valuable for social workers in Minnesota. We wish you every success.

LF:lmn

c: Dr. Sharon Patten

APPENDIX E

NEW HEALTH CARE DIRECTIVE FORM

(B) Choose my health care providers.

(C) Choose where I live and receive care and support when those choices relate to my health care needs.

(D) Review my medical records and have the same rights that I would have to give my medical records to other people.

If I *do not* want my health care agent to have a power listed above in (A) through (D) *or* if I want to *limit* any power in (A) through (D), I *must* say that here:

_____

_____

_____

My health care agent is *not* automatically given the powers listed below in (1) and (2). If I *want* my agent to have any of the powers in (1) and (2), I must *initial* the line in front of the power; then my agent *will* have that power.

_____ (1) To decide whether to donate my organs when I die.

_____ (2) To decide what will happen with my body when I die (burial, cremation).

If I want to say something more about my health care agent's powers or limits on the powers, I can say it here:

_____

_____

_____

Part II: Health Care Instructions

Note: Complete this Part II if you wish to give health care instructions. If you appointed an agent in Part I, completing this Part II is optional but would be very helpful to your agent. However, if you chose not to appoint an agent in Part I, you must complete some or all of this Part II if you wish to make a valid health care directive.

These are instructions for my health care when I am unable to decide or speak for myself. These instructions must be followed (so long as they address my needs).

These are my beliefs and values about my health care. (I know I can change these choices or leave any of them blank)

I want you to know these things about me to help you make decisions about my health care:

My goals for my health care: _____

_____

My fears about my health care: _____

_____

My spiritual or religious beliefs and traditions: _____

_____

My beliefs about when life would be no longer worth living: _____

_____

My thoughts about how my medical condition might affect my family: _____

_____

This is what I want and do not want for my health care (I know I can change these choices or leave any of them blank).

Many medical treatments may be used to try to improve my medical condition or to prolong my life. Examples include artificial breathing by machine connected to a tube in the lungs, artificial feeding or fluids through tubes, attempts to start a stopped heart, surgeries, dialysis, antibiotics, and blood transfusions. Most medical treatments can be tried for a while and then stopped if they do not help.

I have these views about my health care in these situations: (*Note: You can discuss general feelings, specific treatments, or leave any of them blank).*

If I had a reasonable chance of recovery, and were temporarily unable to decide or speak for myself, I would want: _____

_____

If I were dying and unable to decide or speak for myself, I would want: _____

_____

_____

If I were permanently unconscious and unable to decide or speak for myself, I would want:

_____

_____

If I were completely dependent on others for my care and unable to decide or speak for myself, I would want: _____

_____

In all circumstances, my doctors will try to keep me comfortable and reduce my pain. This is how I feel about pain relief if it would affect my alertness or if it could shorten my life:

_____

_____

There are other things that I want or do not want for my health care, if possible:

Who I would like be my doctor: _____

_____

Where I would like to live to receive health care: _____

_____

Where I would like to die and other wishes I have about dying: _____

_____

My wishes about donating parts of my body when I die: _____

_____

My wishes about what happens to my body when I die (cremation, burial): _____

_____

Any other things: _____

_____

Part III: Making the document legal

This document must be signed by me. It also must either be verified by a notary public (Option 1) *or* witnessed by two witnesses (Option 2). It must be dated when it is verified or witnessed.

I am thinking clearly, I agree with everything that is written in this document, and I have made this document willingly.

My signature: _____

Date signed: _____

Date of birth: _____

Address: _____

nnot sign my name, I can ask someone to sign this document for me.

ture of the person who I asked to sign this document for me.

_____

ed name of the person who I asked to sign this document for me.

_____

on 1: Notary Public

presence on _____ (date), _____ (name) acknowledged
r signature on this document or acknowledged that he/she authorized the person signing this
nent to sign on his/her behalf. I am not named as a health care agent or alternate health care agent
s document.

_____

ature of Notary) (Notary Stamp)

on 2: Two Witnesses

vitnesses must sign. Only one of the two witnesses can be a health care provider or an employee of a
1 care provider giving direct care to me on the day I sign this document.

ss *One:*

my presence on _____ (date), _____ (name) acknowledged his/
gnature on this document or acknowledged that he/she authorized the person signing this docu-
to sign on his/her behalf.
am at least 18 years of age.
am not named as a health care agent or an alternate health care agent in this document.
I am a health care provider or an employee of a health care provider giving direct care to the person
above in (A), I must initial this box: [ ]
ify that the information in (i) through (iv) is true and correct.

ature of Witness One) _____

ess: _____

_____

ss *Two:*

my presence on _____ (date), _____ (name) acknowledged his/
gnature on this document or acknowledged that he/she authorized the person signing this docu-
to sign on his/her behalf.
am at least 18 years of age.
am not named as a health care agent or an alternate health care agent in this document.
I am a health care provider or an employee of a health care provider giving direct care to the person
above in (A), I must initial this box: [ ]
ify that the information in (i) through (iv) is true and correct.

ature of Witness One) _____

ess: _____

_____

nder: Keep this document with your personal papers in a safe place (not in a safe deposit box).
signed copies to your doctors, family, close friends, health care agent, and alternate health care
. Make sure your doctor is willing to follow your wishes. This document should be part of your
al record at your physician's office and at the hospital, home care agency, hospice, or nursing facility
e you receive your care.

Abstract

The Study of the Use of Advance Directives
in Minnesota Nursing Homes as Perceived
by Social Workers

DENISE SIGSTAD

JUNE 1999

This study sought to discover the use of advance directives as reported by nursing home social workers. The focus is on residents who are living in nursing homes and are sixty years old or older. One hundred social workers in Minnesota were randomly surveyed on the current rate of advance directive use, barriers to completing the forms, and perceptions from social workers about whether they have or not have adequate knowledge and education to teach about advance directives. A review of the literature on advance directives shows the average use is only 5-18% for the elderly population.

Survey findings confirm that the average use of advance directives is similar to the general average for the elderly population. Common barriers include procrastination, fear of death and dying, dependence on family members to make decisions, and lack of knowledge of advanced directives. Many social workers perceive they have adequate training and education on advance directives, but are open to further information on state laws and medical terminology. Further implications for social work practice include continued research on advance directives. The research shows that even with new forms combining living will and health care power of attorney forms, there is a lack of understanding by the elderly population.